Mental Retardation & Down Syndrome

Mental Retardation

Definition: People with mental retardation mature at a below-average rate and experience unusual difficulty in learning, social adjustment, and economic productivity. Mental retardation is not a disease, nor should it be confused with mental illness.

Incidence: One out of every ten Americans has a person with mental retardation in his or her family -- about 3% of the population of the United States.

Down Syndrome

Definition: Down Syndrome is the most common readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality, where there is an extra chromosome. This extra chromosome changes the orderly development in the body and brain.

Incidence: Approximately 4,000 children with Down Syndrome are born in the United States each year. Although parents of any age may have a child with Down Syndrome, the incidence is higher for women over 35.

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- Attitudinal Quiz about Mental Retardation
- Bibliography of Children's Literature & Audio Visual Materials
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ELEMENTARY SCHOOL

Fingerprinting, Handprinting, Footprinting

Purpose: For students to gain an awareness of and appreciation for individual differences.

Materials: ink pads or tempera paint, magnifying glasses

Activity:

1. Each child makes prints of fingers, hands, foot on a piece of paper. These are compared by small groups of children noting individual differences in size, shape, lines, etc. Magnifying glasses can be used to look at fingerprint detail.

2. Shuffle the hand or foot prints and hand out one to each child. The child needs to go around the room searching for the hand or foot that matches—promoting interaction.

3. These prints can be hung on the wall and can prompt discussion on individual differences and the range of difference within their particular classroom. This can be tied into science lessons on the concept of uniqueness (snowflakes, etc.) and genetics, and to social studies classes about individuality and the human group.

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

ELEMENTARY SCHOOL

Who's a Helper?

Purpose: Students will identify individual strengths and how they can be contributing members of their classroom community.

Materials: Magazines, scissors, tape, markers

Activity: Talk in the class about what help is and how many ways we can help. Ask the children for examples. Pair students and have them locate pictures in magazines which show one person helping another. Tear out the picture(s) and paste it on a sheet of paper. Label the picture in terms of how the people are helping. Have each pair hold up its "helping collage" and tell class members about it.

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

ELEMENTARY SCHOOL

Aunt Blabby Letter Writing Activity

Purpose: To address individual concerns/questions/misconceptions children may have about mental retardation.

Materials: Pencils, pens, paper

Activity:

Aunt Blabby is a fictional character presented to your students as an expert on disability related issues: the Ann Landers for disability questions.

Invite a guest speaker to come to your class/program to talk about mental retardation. A list of resources accompanies this guide and may provide you with ideas on where to find a guest speaker. Ask the students to write a personal response to this experience. Some samples are attached in the materials accompanying this guide. If arranging for a guest speaker is not possible, have students write to Maryland Association for Retarded Citizens (The ARC) or Baltimore Association for Retarded Citizens (BARC) with their questions about mental retardation to request further information.

Meyers, Donald, Patricia Vadasky, Rebecca Fennell, . SibShops. Seattle and London: University of Washington Press, 1985.

Dear Aunt Blabby,
If someone is born blind is there a different jean? If someone is born deaf is there a different jean? Could someone that is retarted be very smart. If someone is born deaf how would they learn to sign, read and write?

Sincerely,

Dear Aunt Blabby,

I have learned lots of things about handicap people. You can be disable, mentaly retarded, blind, deaf, etc. I wish people would help handicap people instead of ignoring them.

1. Why do some people ignore handicap people?

2. Can handicap people die from their handicap?

Why do they do what they do?

Why can't they contral their by movements?

How do they work?

How could they learn?

Can they get red of what thay have? (mental retardanstoin)

Dear Aunt Blabby,
There is a kid in our school, his name is [redacted]. He has C.P. Some times he makes nouses. Kids laught at him. I don't. I don't because thats just his way of getting attantion. I also look over there somes and I see kids helping him. Some times their helping him on the computer.

MIDDLE SCHOOL

Too Many Directions

Purpose: Students will gain understanding of the difficulty persons with mental retardation may encounter in following and remembering directions.

Materials: List of 15 simple directions

Activity:

Choose two children to come up to the front of the room and sit in chairs back to back. Explain that some children with mental retardation or children with certain learning disabilities find it very confusing to follow even a few simple directions. If you told such a child, "Go get the ball and bat and meet me at the playground in 5 minutes." that might be too much information for the child to process at one time. To see how frustrating this would be, read a list of 10 to 15 directions, such as "Stand up, hands on shoulders, turn around, spell your name backwards," etc. Tell the two children that you will read the list through once and then you want them to follow the directions in order. Let a few pairs of children come try this experiment.

Discussion:

Ask the students how they felt trying to remember everything. How would they feel if they were this overwhelmed by other people whenever they were talked to? How could they talk to a child with mental retardation so that the child would feel comfortable and would understand, rather than feel confused?

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

MIDDLE SCHOOL

Critical Incidents/Teasing

Purpose: Students will generate positive options for responding to dealing with social situations where discrimination and ridicule toward persons with developmental disabilities occur.

Materials: None

Activity:

Present a critical incident (only one at a time) to the class in small groups or to the whole class. The advantage of small groups is that each child has a greater opportunity to talk and have input. Sample questions are listed below, or teachers may create their own.

A. Artwork from a special class is hung in the hallway. You are coming back from gym and you see someone scribbling "retard" over one of the pictures. Why do you think the person did that? How would you feel as an observer? How would you feel as the person who drew the picture?

B. You and several of your friends are sitting in the lunchroom at a table where there are some students and a teacher from a special class. You have been eating and talking. You helped a boy open his milk carton. Suddenly, someone you know appears in the lunch line and shouts, "Hey, I see you all are in the right bunch!" How would you feel? Why do you think he did that? What would you do?

C. Your class is in gym and the teacher asks you to all hold hands in a big circle. James moves away from Michael saying, "I'm not going to hold hands with him. He smells!" What would you do? How do you think James feels? How does Michael feel? How would you feel as an observer? What would you do?

Problem solve about what could be done in these situations. Use the format for group problem solving called brainstorming. Brainstorming involves generating as many solution ideas as possible; eliminate nothing, no matter how unrealistic it may seem. You can ask a group to come up with a particular number of alternative solutions (e.g., five), or it can he left open ended. Write on the board each suggestion as it is made. After the suggestions are listed for everyone to see, begin to prioritize them by talking about what the effects of each would be, are they desirable, what would help and hinder the use of each particular approach? As a group, you may not come to consensus about the best approach, but you may identify two or three options that seem most useful. There are no right answers. This kind of activity is helpful for all of us because it gives us an expanded repertoire of ways to respond to daily events, when we have more options, we are less likely to feel victimized by those events.

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY: Human Policy Press, 1978.

MIDDLE SCHOOL

Index Card Activity

Purpose: To help students understand what it might be like to have a disability that made everyday tasks more difficult to accomplish.

Materials: Index Cards and Pens

Activity:

Tell students that you need them to make name cards for their desks as you are passing out the index cards. Have them write their names on one side of the card in their best penmanship. Then ask students to turn the cards over. Tell students to hold the cards up on their foreheads with one hand and to write their name (while the card is on their forehead) on the card with their other hand. Only allow five seconds for them to complete this activity. Generate discussion about the difficulty involved in doing this. Ask students to think about what it might be like if they encountered this level of difficulty in doing everyday tasks.

Guide a discussion about understanding what it might be like to have difficulty completing daily living tasks and how to be more empathetic to persons with intellectual impairments, such as mental retardation.

HIGH SCHOOL

Task Analysis

For persons with developmental disabilities, small steps are important when they are learning something new. Advise students to work in this step-by-step way (task analysis) when helping a friend with a developmental disability.

Ask students to generate a list of five daily tasks; for example, using the phone or making a peanut butter sandwich. Show students how to divide a task into the little steps it takes. Ask students to generate a list of directions for one of these tasks. Keep the directions simple and short. Be orderly. List the steps on the board. To assist students, have a volunteer perform the task in slow motion. Record the steps involved.

Another variation of this activity would be to have students working in pairs, with one student instructing the other student on how to make a peanut butter sandwich. The student making the sandwich should only perform the tasks given by the instructing student. Have students record each step. As a total group, compare the different set of steps each pair generated. Which set of directions seemed easiest?

Class Discussion

-Were students surprised at all the things they needed to know to perform a daily task'?

-How might this affect someone who is a slower learner?

-If someone can't complete a whole task independently, is it important for them to do a part of the task or should someone just do it for them?

Place emphasis on the capability of people with mental retardation to learn though it may take longer. It is important for people to have opportunities to learn to do things that their peer group is learning, i. e., independent living skills.

HIGH SCHOOL

What Can You Do? Self-Inventory and Student Review

Purpose: Students will develop awareness of vocational opportunities and the importance of work for adults with mental retardation.

Materials: Note pads, scrap book, newspaper

Activity:

Have the students list (in their notebooks or teacher at board) what jobs they do. Include after-school jobs such as babysitting, watering plants, working in a restaurant, and so forth. Break down the jobs into necessary skills. Ask if these various jobs could be performed if one had a disability. Ask some students to explain or act out how the job might be handled by someone with blindness, deafness, or who was in a wheelchair. Could the job be performed by someone who is labeled mentally retarded? If the students are unclear, perhaps a field trip could be arranged to a vocational program so that they could see first-hand how jobs are handled by individuals with a disability.

Ask the students to interview each other about their jobs. What do they have to do? What is the most important thing? Could students with disabilities do those things? In what ways could they be helped?

Discuss some things which need to be done around the house or neighborhood for which someone might receive pay. Could a person with a disability do the jobs? Why or why not? Which would he/she like most and least? Do preferences necessarily have anything to do with ability? Does getting paid for a job have something to do with ability? What effect does disability play in getting paid for a job?

Barnes, Ellen, Carol Berrigan, and Douglas Biklen. What's the Difference: Teaching Positive Attitudes Toward People with Disabilities. Syracuse, NY. Human Policy Press, 1978.

HIGH SCHOOL

Two Syllable Word Sentences

Purpose: To help students understand what it might be like to have a disability that made learning and everyday activities more difficult to accomplish.

Materials: Pencil, paper

Activity:

You will need an introductory activity such as a movie, or book that deals with disability. The material accompanying this guide includes an audio visual and literature bibliography of local resources. You may want to invite a guest speaker to come to your class/program to talk about mental retardation. A list of resources accompanies this guide and may provide you with ideas on where to find a guest speaker.

After the "prompting" activity ask students to write a personal response sentence using only two-syllable words. Tell students that you will be collecting their responses and that they need to put their names and the date in the top left hand corner. Allow them only a short period of time (2 minutes) to complete this task. Once you have collected all the responses, ask students how they felt about the activity. Were they frustrated, were they mad at you for asking them to do something in which they could not be successful, did they give up, were they embarrassed that it was so difficult for them? Ask students to think of ways/strategies that would have helped them be more successful, i.e., working with a partner, having more time, having teacher assistance, using reference material. Relate their experiences to difficulties some people with mental retardation have on a daily basis doing things we may take for granted. Generate ideas about how to assist someone in completing everyday tasks.

National Information Center
for Children and Youth
with Disabilities

NICHCY

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MENTAL RETARDATION

✧ *Definition* ✧

People with mental retardation are those who develop at a below average rate and experience difficulty in learning and social adjustment. The regulations for the Individuals with Disabilities Education Act (IDEA) provide the following technical definition for mental retardation:

> "Mental retardation means significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child's educational performance."

"General intellectual functioning" typically is measured by an intelligence test. Persons with mental retardation usually score 70 or below on such tests. "Adaptive behavior" refers to a person's adjustment to everyday life. Difficulties may occur in learning, communication, social, academic, vocational, and independent living skills.

Mental retardation is not a disease nor should it be confused with mental illness. Children with mental retardation become adults; they do not remain "eternal children." They do learn, but slowly and with difficulty.

Probably the greatest number of children with mental retardation have chromosome abnormalities. Other biological factors include (but are not limited to): asphyxia (lack of oxygen); blood incompatibilities between the mother and fetus; and maternal infections, such as rubella or herpes. Certain drugs have also been linked to problems in fetal development.

✧ *Incidence* ✧

Some studies suggest that approximately 1% of the general population has mental retardation (when both intelligence and adaptive behavior measures are used). According to data reported to the U.S. Department of Education by the states, in the 1996-97 school year, 594,025 students ages 6-21 were classified as having mental retardation and were provided services by the public schools. This figure does not include students reported as having multiple disabilities or those in non-categorical special education pre-school programs who may also have mental retardation.

✧ *Characteristics* ✧

Many authorities agree that people with mental retardation develop in the same way as people without mental retardation, but at a slower rate. Others suggest that persons with mental retardation have difficulties in particular areas of basic thinking and learning such as attention, perception, or memory. Depending on the extent of the impairment—mild, moderate, severe, or profound—individuals with mental retardation will develop differently in academic, social, and vocational skills.

✧ *Educational Implications* ✧

Persons with mental retardation have the capacity to learn, to develop, and to grow. The great majority of these citizens can become productive and full participants in society.

Appropriate educational services that begin in infancy and continue throughout the developmental period and beyond will enable children with mental retardation to develop to their fullest potential.

As with all education, modifying instruction to meet individual needs is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

MENTAL RETARDATION

In teaching persons with mental retardation, it is important to:

- Use concrete materials that are interesting, age-appropriate, and relevant to the students;
- Present information and instructions in small, sequential steps and review each step frequently;
- Provide prompt and consistent feedback;
- Teach these children, whenever possible, in the same school they would attend if they did not have mental retardation;
- Teach tasks or skills that students will use frequently, in such a way that students can apply the tasks or skills in settings outside of school; and
- Remember that tasks that many people learn without instruction may need to be structured, or broken down into small steps or segments, with each step being carefully taught.

Children and adults with mental retardation need the same basic services that all people need for normal development. These include education, vocational preparation, health services, recreational opportunities, and many more. In addition, many persons with mental retardation need specialized services for special needs. Such services include diagnostic and evaluation centers; special early education opportunities, beginning with infant stimulation programs and continuing through preschool; and educational programs that include age-appropriate activities, functional academics, transition training, and opportunities for independent living and competitive employment to the maximum extent possible.

✧ *Resources* ✧

Smith, R. (Ed.). (1993). *Children with mental retardation: A parents' guide.* Available from Woodbine House. 6510 Bells Mill Rd., Bethesda, MD 20817. [Telephone: 1-800-843-7323; (301) 897-3570.]

Trainer, M. (1991). *Differences in common: Straight talk on mental retardation, Down syndrome, and life.* Rockville, MD: Woodbine House. (See telephone number above.)

✧ *Organizations* ✧

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
1-800-433-5255 (Toll-free); (817) 261-6003
(817) 277-0553 (TTY)
E-Mail: thearc@metronet.com
URL: http://thearc.org/welcome.html

American Association on Mental Retardation (AAMR)
444 N. Capitol Street N.W., Suite 846
Washington, D.C. 20001
1-800-424-3688 (Toll-free, outside of DC)
(202) 387-1968
URL: http://www.aamr.org

National Down Syndrome Congress
1605 Chantilly Drive Suite 250
Atlanta, GA 30324
1-800-232-6372 (Toll-free); (404) 633-1555
E-Mail: NDSCcenter@aol.com
URL: http://www.carol.net/~ndsc

National Down Syndrome Society
666 Broadway, Suite 810
New York, NY 10012
1-800-221-4602 (Toll-free); (212) 460-9330
(212) 979-2873 (Fax)
E-Mail: info@ndss.org
URL: http://ndss.org

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The Arc

a national organization on mental retardation

Q&A

Introduction to Mental Retardation

What is mental retardation?

An individual is considered to have mental retardation based on the following three criteria: intellectual functioning level (IQ) is below 70-75; significant limitations exist in two or more adaptive skill areas; and the condition is present from childhood (defined as age 18 or less) (AAMR, 1992).

What are the adaptive skills essential for daily functioning?

Adaptive skill areas are those daily living skills needed to live, work and play in the community. They include communication, self-care, home living, social skills, leisure, health and safety, self-direction, functional academics (reading, writing, basic math), community use and work.

Adaptive skills are assessed in the person's typical environment across all aspects of an individual's life. A person with limits in intellectual functioning who does not have limits in adaptive skill areas may not be diagnosed as having mental retardation.

How many people are affected by mental retardation?

The Arc reviewed a number of prevalence studies in the early 1980s and concluded that 2.5 to 3 percent of the general population have mental retardation (The Arc, 1982).

Based on the 1990 census, an estimated 6.2 to 7.5 million people have mental retardation. Mental retardation is 10 times more common than cerebral palsy and 28 times more prevalent than neural tube defects such as spina bifida. It affects 25 times as many people as blindness (Batshaw, 1997).

Mental retardation cuts across the lines of racial, ethnic, educational, social and economic backgrounds. It can occur in any family. One out of ten American families is directly affected by mental retardation.

How does mental retardation affect individuals?

The effects of mental retardation vary considerably among people, just as the range of abilities varies considerably among people who do not have mental retardation. About 87 percent will be mildly affected and will be only a little slower than average in learning new information and skills. As children, their mental retardation is not readily apparent and may not be identified until they enter school. As adults, many will be able to lead independent lives in the community and will no longer be viewed as having mental retardation.

The remaining 13 percent of people with mental retardation, those with IQs under 50, will have serious limitations in functioning. However, with early intervention, a functional education and appropriate supports as an adult, all can lead satisfying lives in the community.

How is mental retardation diagnosed?

The AAMR process for diagnosing and classifying a person as having mental retardation contains three steps and describes the system of supports a person needs to overcome limits in adaptive skills.

The first step in diagnosis is to have a qualified person give one or more standardized intelligence tests and a standardized adaptive skills test, on an individual basis.

The second step is to describe the person's strengths and weaknesses across four dimensions. The four dimensions are:

1. Intellectual and adaptive behavior skills
2. Psychological/emotional considerations
3. Physical/health/etiological considerations
4. Environmental considerations

Strengths and weaknesses may be determined by formal testing, observations, interviewing key people in the individual's life, interviewing the individual, interacting with the person in his or her daily life or a combination of these approaches.

The third step requires an interdisciplinary team to determine needed supports across the four dimensions. Each support identified is assigned one of four levels of intensity - intermittent, limited, extensive, pervasive.

Intermittent support refers to support on an "as needed basis." An example would be support that is needed in order for a person to find a new job in the event of a job loss. Intermittent support may be needed occasionally by an individual over the lifespan, but not on a continuous daily basis.

Limited support may occur over a limited time span such as during transition from school to work or in time-limited job training. This type of support has a limit on the time that is needed to provide appropriate support for an individual.

Extensive support in a life area is assistance that an individual needs on a daily basis that is not limited by time. This may involve support in the home and/or support in work. Intermittent, limited and extensive supports may not be needed in all life areas for an individual.

Pervasive support refers to constant support across environments and life areas and may include life-sustaining measures. A person requiring pervasive support will need assistance on a daily basis across all life areas.

What does the term "mental age" mean when used to describe the person's functioning?

The term mental age is used in intelligence testing. It means that the individual received the same number of correct responses on a standardized IQ test as the average person of that age in the sample population.

Saying that an older person with mental retardation is like a person of a younger age or has the "mind" or "understanding" of a younger person is incorrect usage of the term. The mental age only refers to the intelligence test score. It does not describe the level and nature of the person's experience and functioning in aspects of community life.

What are the causes of mental retardation?

Mental retardation can be caused by any condition which impairs development of the brain before birth, during birth or in the childhood years. Several hundred causes have been discovered, but in about one-third of the people affected, the cause remains unknown. The three major known causes of mental retardation are Down syndrome, fetal alcohol syndrome and fragile X.

The causes can be categorized as follows:

- **Genetic conditions** - These result from abnormality of genes inherited from parents, errors when genes combine, or from other disorders of the genes caused during pregnancy by infections, overexposure to x-rays and other factors. More than 500 genetic diseases are associated with mental retardation. Some examples include PKU (phenylketonuria), a single gene disorder also referred to as an inborn error of metabolism because it is caused by a defective enzyme. Down syndrome is an example of a chromosomal disorder. Chromosomal disorders happen sporadically and are caused by too many or too few chromosomes, or by a change in structure of a chromosome. Fragile X syndrome is a single gene disorder located on the X chromosome and is the leading inherited cause of mental retardation.
- **Problems during pregnancy** - Use of alcohol or drugs by the pregnant mother can cause mental retardation. Recent research has implicated smoking in increasing the risk of mental retardation. Other risks include malnutrition, certain environmental contaminants, and illnesses of the mother during pregnancy, such as toxoplasmosis, cytomegalovirus, rubella and syphillis. Pregnant women who are infected with HIV may pass the virus to their child, leading to future neurological damage.
- **Problems at birth** - Although any birth condition of unusual stress may injure the infant's brain, prematurity and low birth weight predict serious problems more often than any other conditions.
- **Problems after birth** - Childhood diseases such as whooping cough, chicken pox, measles, and Hib disease which may lead to meningitis and encephalitis can damage the brain, as can accidents such as a blow to the head or near drowning. Lead, mercury and other environmental toxins can cause irreparable damage to the brain and nervous system.
- **Poverty and cultural deprivation** - Children in poor families may become mentally retarded because of malnutrition, disease-producing conditions, inadequate medical care and environmental health hazards. Also, children in disadvantaged areas may be deprived of many common cultural and day-to-day experiences provided to other youngsters. Research suggests that such under-stimulation can result in irreversible damage and can serve as a cause of mental retardation.

Can mental retardation be prevented?

During the past 30 years, significant advances in research have prevented many cases of mental retardation. For example, every year in the United States, we prevent:

- 250 cases of mental retardation due to phenylketonuria (PKU) by newborn screening and dietary treatment;
- 1,000 cases of mental retardation due to congenital hypothyroidism thanks to newborn screening and thyroid hormone replacement therapy;
- 1,000 cases of mental retardation by use of anti-Rh immune globulin to prevent Rh disease and severe jaundice in newborn infants;
- 5,000 cases of mental retardation caused by Hib diseases by using the Hib vaccine;
- 4,000 cases of mental retardation due to measles encephalitis thanks to measles vaccine; and
- untold numbers of cases of mental retardation caused by rubella during pregnancy thanks to rubella vaccine (Alexander, 1998).

Other interventions have reduced the chance of mental retardation. Removing lead from the environment reduces brain damage in children. Preventive interventions such as child safety seats and bicycle helmets reduce head trauma. Early intervention programs with high-risk infants and children have shown remarkable results in reducing the predicted incidence of subnormal intellectual functioning.

Finally, early comprehensive prenatal care and preventive measures prior to and during pregnancy increase a woman's chances of preventing mental retardation. Pediatric AIDS is being reduced by AZT treatment of the mother during pregnancy, and dietary supplementation with folic acid reduces the risk of neural tube defects.

Research continues on new ways to prevent mental retardation, including research on the development and function of the nervous system, a wide variety of fetal treatments, and gene therapy to correct the abnormality produced by defective genes.

References

American Association on Mental Retardation. (1992). *Mental Retardation: Definition, Classification, and Systems of Supports, 9th Edition.* Washington, DC.

Alexander, D. (1998). Prevention of Mental Retardation: Four Decades of Research. *Mental Retardation and Developmental Disabilities Research Reviews.* 4: 50-58

Batshaw, M. (1997). *Children With Disabilities.* Baltimore: Paul H. Brookes Publishing Co.

The Arc. (1982). *The Prevalence of Mental Retardation.* (out-of-print).

Where can I go for more information?

You will find a wide variety of information on The Arc's home page on the World Wide Web: The Arc.org/. You can also contact staff at the national headquarters for more information.

Or, call your local chapter of The Arc.

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National Information Center
for Children and Youth
with Disabilities

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DOWN SYNDROME

✧ *Definition* ✧

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. This extra chromosome changes the orderly development of the body and brain. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth.

✧ *Incidence* ✧

Approximately 4,000 children with Down syndrome are born in the U.S. each year, or about 1 in every 800 to 1,000 live births. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35. Most common forms of the syndrome do not usually occur more than once in a family.

✧ *Characteristics* ✧

There are over 50 clinical signs of Down syndrome, but it is rare to find all or even most of them in one person. Some common characteristics include:

- Poor muscle tone;
- Slanting eyes with folds of skin at the inner corners (called epicanthal folds);
- Hyperflexibility (excessive ability to extend the joints);
- Short, broad hands with a single crease across the palm on one or both hands;
- Broad feet with short toes;
- Flat bridge of the nose;
- Short, low-set ears;
- Short neck;
- Small head;
- Small oral cavity; and/or
- Short, high-pitched cries in infancy.

Individuals with Down syndrome are usually smaller than their nondisabled peers, and their physical as well as intellectual development is slower.

Besides having a distinct physical appearance, children with Down syndrome frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are higher in individuals with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one third of babies born with Down syndrome have heart defects, most of which are now successfully correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes these individuals more prone to injury if they participate in activities which overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from sports and activities which place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

Children with Down syndrome may have a tendency to become obese as they grow older. Besides having negative social implications, this weight gain threatens these individuals' health and longevity. A supervised diet and exercise program may help reduce this problem.

✧ *Educational and Employment Implications* ✧

Shortly after a diagnosis of Down syndrome is confirmed, parents should be encouraged to enroll their child in an infant development/early intervention program. These programs offer parents special instruction in teaching their child language, cognitive, self-help, and social skills, and specific exercises for gross and fine motor development. Research has shown that stimulation dur-

ing early developmental stages improves the child's chances of developing to his or her fullest potential. Continuing education, positive public attitudes, and a stimulating home environment have also been found to promote the child's overall development.

Just as in the normal population, there is a wide variation in mental abilities, behavior, and developmental progress in individuals with Down syndrome. Their level of retardation may range from mild to severe, with the majority functioning in the mild to moderate range. Due to these individual differences, it is impossible to predict future achievements of children with Down syndrome.

Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. It may be effective to emphasize concrete concepts rather than abstract ideas. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has proven successful. Improved public acceptance of persons with disabilities, along with increased opportunities for adults with disabilities to live and work independently in the community, have expanded goals for individuals with Down syndrome. Independent Living Centers, group-shared and supervised apartments, and support services in the community have proven to be important resources for persons with disabilities.

✧ *Resources* ✧

Brill, M.T. (1993). *Keys to parenting a child with Down syndrome.* Hauppauge, NY: Barron's. (Telephone: 1-800-645-3476.)

Cunningham, C. (1996). *Understanding Down syndrome: An introduction for parents.* Cambridge,MA: Brookline. (Telephone: 1-800-666-2665.)

National Down Syndrome Society. *This baby needs you even more.* (See address below.)

Pueschel, S.M. (Ed.). (1990). *A parent's guide to Down syndrome: Toward a brighter future.* Baltimore, MD: Paul H. Brookes. (Telephone: 1-800-638-3775.)

Uhruh, J.F. (1994). *Down syndrome: Successful parenting of children with Down syndrome.* Eugene, OR: Fern Ridge Press. [Telephone: (503) 485-8243.]

Woodbine House publishes a series of books on Down syndrome, including: *Differences in common: Straight talk about mental retardation, Down syndrome, and life* (1991); *Communication skills in children with Down syndrome: A guide for parents* (1994); *Medical and surgical care for children with Down syndrome: A guide for parents* (1995, May); and *Babies with Down syndrome: A new parent's guide* (1995, July); *Teaching reading to children with Down Syndrome* (1995); and *Gross motor skills in children with Down Syndrome* (1997). Contact Woodbine House, 6510 Bells Mill Rd., Bethesda, MD 20817. (Telephone: 1-800-843-7323.)

✧ *Organizations* ✧

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(404) 633-1555; 1-800-232-6372 (Toll Free)
E-Mail: NDSCcenter@aol.com
URL: http://www.carol.net/~ndsc

National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012-2317
(212) 460-9330; 1-800-221-4602 (Toll Free)
E-Mail: info@ndss.org
URL: http://ndss.org

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003; 1-800-433-5255
E-Mail: thearc@metronet.com
URL: http://thearc.org/welcome.html

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"Disability Myths"

People with disabilities have been the subject of many myths and misconceptions which interfere with their acceptance into the mainstream of society. To help deflate some of the major myths about disabilities, this information which appears in the "Disabilities Resource Guide" of the KIDS Project, Center for Independent Living, Berkeley, California, is presented.

Prevalent Myths about People with Mental Retardation

MYTH: People with mental retardation have no feelings.
FACT: People with mental retardation have the same range of feelings as people without mental retardation.

MYTH: People with mental retardation are childish and should be treated as children.
FACT: People with mental retardation are capable of developing age-appropriate behaviors. A teenager with mental retardation should be treated like any other teenager. An adult with mental retardation should be treated as an adult.

MYTH: People with mental retardation are asexual or sexually promiscuous and should not be taught about sex.
FACT: People with mental retardation are no more asexual or sexually promiscuous than anyone else. They should receive sex education and be allowed normal sexual expression like anyone else.

MYTH: People with mental retardation are often violent and become criminals when they grow up.
FACT: People with mental retardation are no more likely to be violent or engage in criminal activity than people without mental retardation.

MYTH: People with mental retardation are dull and boring. They don't understand even the basics of life.
FACT: People with mental retardation are no more dull and boring than anyone else. People with mental retardation often make astonishingly astute observations about people, events, and life in general.

TEST ON MENTAL RETARDATION

Circle the letter A if you agree with the statement, D if you disagree, or N if you have no opinion either way.

1. Mental retardation is a disease.	A	D	N
2. Most people with mental retardation look and act differently than normal people.	A	D	N
3. A person can develop mental retardation after birth.	A	D	N
4. A child can be born with mental retardation and later be cured completely.	A	D	N
5. Children can have mental retardation if their mothers contracted certain diseases in the early stages of pregnancy.	A	D	N
6. There is only one basic cause of retardation.	A	D	N
7. Most children who cannot see, hear, or walk will develop mental retardation.	A	D	N
8. Children with mental retardation are more like normal children than different from them.	A	D	N
9. Very intelligent parents don't have to worry with mild retardation.	A	D	N
10. All people with mental retardation act and think alike.	A	D	N
11. Most people with mental retardation should be in institutions.	A	D	N
12. Education can help most people with mental retardation.	A	D	N
13. Some people with mental retardation can work at jobs.	A	D	N
14. People with mental retardation should not get married and have children of their own.	A	D	N
15. Children with mental retardation should be placed in the same classes as normal children.	A	D	N
16. People with mental retardation don't know enough to teach a normal person anything.	A	D	N
17. No serious drawbacks are involved when people of normal intelligence marry people about having a child with mental retardation.	A	D	N
18. People with mental retardation can be made much better or much worse depending on how they are treated by society.	A	D	N

Bibliography

Books

Anderson, Rachel. *The Bus People*. New York: Henry Holt, 1992.

Baldwin, Anne Norris. *A Little Time*. New York: Viking, 1978. 96 pp. $8.95. (Ages 8-12)

Bolnick, Jamie Pastor. *Winnie: "My Life in the Institution."* New York: St. Martin's, 1985. 248 pp. $14.95

Brightman, Alan J. *Like Me*. Boston, MA: Little, Brown and Co., 1976.

Brown, Tricia. *Someone Special Just Like You*. Holt, Rinehart and Winston, 1984. (primary)

Byers, Betsy. *The Summer of the Swans*. New York: Viking Press, 1970.

Cairo, Shelley. *Our Brother Has Down's Syndrome: An Introduction for Children*. Willowdale, Ontario: Annick Press, 1985. $6.00. (Ages 5-8)

Carpelan, Bo. *Bow Island*. New York: Delacorte Press, 1971.

Carrick, Carol. *Stay Away from Simon*. New York: Clarion Books, 1985. 63 pp. $10.95. (Ages 8-12)

Cassedy, Sylvia. *M.E. and Morton*. New York: Thomas Y. Crowell, 1987. 312 pp. $12.95. (Ages 12-15)

Christopher, Matthew. *Long Shot for Paul*. Boston: Little, Brown, and Company, 1966.

Cleaver, Vera and Cleaver, Bill. *Me Too*. New York: J.B. Lippincott, 1973.

Clifton, Lucille. *My Friend Jacob*. E.P. Dutton, 1980. (primary)

Cohen, Floreva. *My Special Friend*. New York: Board of Jewish Education, 1986. $10.95; $5.95 (paper). (Ages 5-8)

Cohen, Miriam. *It's George!* New York: Greenwillow Books, 1988. $11.95. (Ages 4-8)

Conley, Jane Leslie. *Crazy Lady!* New York: Harper/Collins, 1993.

Dougan, Terrell; Isbell, Lyn; Vyas, Patricia, comps. *We Have Been There*. Nashville: Abingdon, 1983. 206 pp. $10.95 (paper)

Forrai, Maria and Anders, Rebecca. *A Look at Mental Retardation*. Minneapolis: Lerner Publications Co., 1976.

Grollman, Sharon Hya. *More Time to Grow*. Boston: Beacon Press, 1977.

Hamilton, Virginia. *Sweet Whispers, Brother Rush*. Philomel, 1982. (middle/high)

Hasler, Eveline. *Martin is Our Friend.* Nashville: Abingdon, 1981. $7.75. (Ages 4-7)

Hunt, Irene. *The Everlasting Hills.* New York: Charles Scribner's Sons, 1985. 184 pp. $12.95. (Ages 10-14)

Koob, Theodore. *Deep Search.* Philadelphia: J.B. Lippincott, 1969.

Litchfield, Ada B. *Making Room for Uncle Joe*. Niles, Ill.: Albert Whitman, 1984. $10.25. (Ages 7-10)

Little, Jean. *Take Wing*. Boston: Little, Brown, & Co., 1968.

Luis, Earlene W. and Millar, Barbara. *Listen Lissa*. New York: Dodd, Mead, and Co., 1968.

Marek, Margot. *Different Not Dumb*. Franklin Watts, 1985. (primary)

Miner, Jane Claypool. *She's My Sister: Having a Retarded Sister*. Crestwood House, 1982. (middle/high)

Rabe, Berniece. *Where's Chimpy?* Niles, Ill.: Albert Whitman, 1988. $11.95. (Ages 4-8)

Reynolds, Pamela. *A Different Kind of Sister*. New York: Lothrop, Lee & Shepard Co., 1968.

Scott, Sharon. *Not Better...Not Worse...Just Different.* Amherst, Mass.: Human Resource Development Press, 1992.

Shalom, Debra Buchbinder. *Special Kids Make Special Friends*. Bellmore, NY: Association for Children with Down Syndrome, 1984. 43 pp. $5.00 (paper). (Ages 3-6)

Shyer, Marlene Fanta. *Welcome Home, Jellybean*. New York: Macmillan, Alladin Books, 1978. 152 pp. $3.95 (paper). (Ages 12-15)

Slepian, Jan. *Risk 'n Roses*. New York: Philomel Books, 1990.

Sobol, Harriet Langsman. *My Brother Steven is Retarded.* New York: Macmillan, 1977. 26 pp. $8.95. (Ages 6-10)

Stefanik, Alfred T. *Copycat Sam: Developing Ties with a Special Child.* New York: Human Sciences Press, 1982. $13.95. (Ages 6-10)

Thompson, Mary. *My Brother Matthew*. Rockville, Md.: Woodbine House, 1992.

Wright, Betty Ren. *My Sister Is Different*. Milwaukee: Raintree, 1981. 31 pp. $15.35. (Ages 5-8)

Wrightson, Patricia. *A Racecourse for Andy*. New York: Harcourt, Brace and World, 1968.

AUDIO VISUAL

New Life in the Neighborhood: Bob Perske. Videotape, 2 hours. Athens, GA: STARS (Systems and Resource Services), 1982.

Special Buddies in the Park. Videotapes (4), 30 minutes each. Bloomington: Offices of Special Services (612)887-9604.

With a Little Help From My Friends. Videotape, 60 minutes. Richmond Hill, Ontario: The Roeher Institute, 1988.

RESOURCE ORGANIZATIONS

State/National Resource Organizations

The Arc of The United States
500 East Border Street
Arlington, TX 76010
800-433-5255

The Arc of Maryland
49 Old Solomon's Island Road
Suite 205
Annapolis, MD 21401
410-571-9320

American Association on Mental Retardation
444 North Capitol Street
Suite 846
Washington, DC 20001
800-424-3688

National Information Center for Handicapped Children and Youth
P.O. Box 1492
Washington, DC 20013
703-893-6061

Exceptional Parent Magazine
605 Commonwealth Avenue
Boston, MA 02215
617-536-8961

National Rehabilitation Information Center
8455 Colesville Road
Silver Spring, MD 20910
800-346-3742

National Down Syndrome Congress
1605 Chantilly Drive
Suite 250
Atlanta, GA 30324
800-232-6372

National Down Syndrome Society
666 Broadway
New York, NY
800-221-4602

Council for Exceptional Children Service Agencies
1920 Association Drive
Reston, VA 22091
800-336-3728

Local Organizations

Maryland Association for Retarded Citizens (The ARC)
410-974-6139

Baltimore Association for Retarded Citizens (BARC)
410-296-2272

Baltimore County Division of Developmental Disabilities
410-887-4411

Maryland Developmental Disabilities Council
410-333-3688

For an expanded list of recommended films, literature, and resources on disabilities, send a self-addressed, stamped envelope to:
National Easter Seal Society, FRIENDS WHO CARE Resource List, 70 East Lake Street, Chicago, IL 60601.